

AMENDED IN SENATE MAY 7, 2013
AMENDED IN SENATE APRIL 22, 2013
AMENDED IN SENATE APRIL 1, 2013

SENATE BILL

No. 222

Introduced by Senator Padilla

February 11, 2013

An act to add Chapter 2.6 (commencing with Section 56.18) to Part 2.6 of Division 1 of the Civil Code, relating to genetic information.

LEGISLATIVE COUNSEL'S DIGEST

SB 222, as amended, Padilla. Genetic information: privacy.

Existing law prohibits discrimination on the basis of an individual's genetic information. Existing law protects the genetic test result contained in the medical records of an applicant to, or enrollee of, a health care service plan. Existing law establishes civil and criminal penalties for the negligent or willful disclosure of a persons genetic test results, as specified.

This bill would enact the Genetic Information Privacy Act, which would declare that an individual's genetic information is protected by the right of privacy. The bill would prohibit any person from collecting, storing, analyzing, or disclosing genetic information without the written authorization of the individual to whom the information pertains, and would include related findings and declarations. It also would prescribe specific circumstances under which genetic information may be collected, stored, analyzed, or disclosed without the authorization. The bill would establish civil and criminal penalties for a violation of its provisions. By creating new crimes, this bill would impose a state-mandated local program.

The California Constitution requires the state to reimburse local agencies and school districts for certain costs mandated by the state. Statutory provisions establish procedures for making that reimbursement.

This bill would provide that no reimbursement is required by this act for a specified reason.

Vote: majority. Appropriation: no. Fiscal committee: yes.
State-mandated local program: yes.

The people of the State of California do enact as follows:

1 SECTION 1. The Legislature finds and declares all of the
2 following:

3 (a) On October 11, 2012, the Presidential Commission for the
4 Study of Bioethical Issues (commission) released a report titled
5 “Privacy and Progress in Whole Genome Sequencing,”
6 recommending the adoptions of policies to help ensure privacy
7 and security, as the field of genomics advances.

8 (b) Various national and state policies are in place to protect
9 personally identifiable health information and records.

10 (c) The commission urges federal and state governments to
11 ensure a consistent floor of privacy protections covering whole
12 genome sequencing data regardless of how they were obtained.

13 (d) Policies should protect individual genetic information by
14 prohibiting the unauthorized use of surreptitious collection.

15 (e) It is the intent of the Legislature to enact legislation that
16 would protect individuals from the unauthorized collection, storage,
17 and disclosure of their genetic information.

18 (f) It is the intent of the Legislature to enact legislation that
19 would ensure that genetic information is personal information that
20 is not collected, stored, or disclosed without the individual’s
21 authorization.

22 (g) It is the intent of the Legislature to enact legislation that
23 would provide protections for the collection, storage, and
24 authorized use of genetic information.

25 (h) It is the intent of the Legislature to enact legislation that
26 would promote the use of genetic information for legitimate
27 reasons, including, but not limited to, health care, research,
28 advancement of medicine, and educational purposes, as the field
29 of genomics advances.

1 SEC. 2. Chapter 2.6 (commencing with Section 56.18) is added
2 to Part 2.6 of Division 1 of the Civil Code, to read:

3
4 CHAPTER 2.6. GENETIC PRIVACY
5

6 56.18. (a) This chapter shall be known, and may be cited, as
7 the Genetic Information Privacy Act.

8 (b) For purposes of this chapter, the following definitions apply:

9 (1) “Deidentified data” is health information that does not
10 identify an individual, with respect to which there is no reasonable
11 basis to believe that the information can be used to identify an
12 individual.

13 (2) “DNA sample” means a tissue, fluid, or other bodily sample
14 of an individual on which a DNA analysis can be carried out.

15 (3) “Genetic characteristic” means any—scientifically or
16 medically identifiable gene or chromosome, or alteration thereof,
17 that is known to be a cause of a disease or disorder, or that is
18 determined to be associated with a statistically increased risk of
19 development of a disease or disorder, and that is presently not
20 associated with any symptoms of any disease or disorder. *that may*
21 *be tested to determine the existence or risk of a disease, disorder,*
22 *trait, propensity, or syndrome, or to identify an individual or a*
23 *blood relative, or to establish or disprove paternity, or to achieve*
24 *other non-health-related purposes.*

25 (4) (A) “Genetic information” means information about any of
26 the following:

27 (i) An individual’s genetic tests.

28 (ii) The genetic tests of that individual’s family members.

29 (iii) The manifestation of disease or disorder in family members
30 of the individual, generally referred to as family medical history.

31 (iv) An individual’s request for, or receipt of, genetic services,
32 or the participation in clinical research that includes genetic
33 services by the individual or a family member of the individual.

34 (v) The genetic information of a fetus carried by an individual
35 or by a pregnant woman who is a family member of the individual
36 and the genetic information of any embryo legally held by the
37 individual or family member using an assisted reproductive
38 technology.

39 ~~(B) Genetic information does not include information about the~~
40 ~~sex or age of the individual, the sex or age of family members, or~~

1 information about the race or ethnicity of the individual or family
2 members that is not derived from a genetic test.

3 (B) “Genetic information” also includes a DNA sample.

4 (5) “Genetic service” means a genetic test, genetic education,
5 or genetic counseling, including obtaining, interpreting, or
6 assessing genetic information.

7 (6) “Genetic test” means a ~~genetic test; genetic counseling,~~
8 ~~including obtaining, interpreting, or assessing genetic information;~~
9 ~~or genetic education.~~ *test for determining the presence or absence*
10 *of genetic characteristics in the individual or in the individual’s*
11 *blood relatives, including tests of nucleic acids such as DNA, RNA,*
12 *and mitochondrial DNA, chromosomes, or proteins, in order to*
13 *diagnose or determine a genetic characteristic.*

14 (7) “Person” means a natural person, trust or estate, partnership,
15 corporation, *limited liability company*, professional association or
16 corporation, or other entity, public or private.

17 56.18.1. (a) Genetic information is protected by the right of
18 privacy pursuant to Section 1 of Article I of the California
19 Constitution and, notwithstanding subdivision (c) of Section 56.10,
20 or any other law, shall not be collected, stored, analyzed, or
21 disclosed without the written authorization of the individual to
22 whom the information pertains.

23 (b) Any person who negligently violates subdivision (a) shall
24 be assessed a civil penalty in an amount not to exceed one thousand
25 dollars (\$1,000) plus court costs, as determined by the court, which
26 penalty and costs shall be paid to the individual to whom the
27 genetic information pertains.

28 (c) Any person who willfully violates subdivision (a) shall be
29 assessed a civil penalty in an amount not less than one thousand
30 dollars (\$1,000) and not more than five thousand dollars (\$5,000)
31 plus court costs, as determined by the court, which penalty and
32 costs shall be paid to the individual to whom the genetic
33 information pertains.

34 (d) Any person who willfully or negligently violates subdivision
35 (a), where the violation results in economic, bodily, or emotional
36 harm to the individual to whom the genetic information pertains,
37 is guilty of a misdemeanor punishable by a fine not to exceed ten
38 thousand dollars (\$10,000).

39 (e) In addition to the penalties listed in subdivisions (b) and (c),
40 a person who commits an act described in subdivision (b) or (c)

1 shall be liable to the person to whom the genetic information
2 pertains for all actual damages, including damages for economic,
3 bodily, and emotional harm that is proximately caused by that act.

4 (f) Each violation of this section is a separate and actionable
5 offense.

6 (g) (1) Any person or entity that wishes to obtain genetic
7 information, other than a person or entity authorized to receive
8 genetic information pursuant to subdivision (h), shall obtain a valid
9 authorization for the release of that information. The written
10 authorization required by this subdivision shall do all of the
11 following:

12 ~~(1)~~

13 (A) Be written in plain language and in a typeface no smaller
14 than 14-point type.

15 ~~(2)~~

16 (B) Be dated and signed by the individual or a person authorized
17 to act on behalf of the individual.

18 ~~(3)~~

19 (C) Specify the types of persons authorized to disclose
20 information about the individual.

21 ~~(4)~~

22 (D) Specify the nature of the information authorized to be
23 disclosed.

24 ~~(5)~~

25 (E) State the name or functions of the persons or entities
26 authorized to receive the information.

27 ~~(6)~~

28 (F) Specify the purposes for which the information is being
29 collected.

30 ~~(7)~~

31 (G) Specify the length of time the authorization shall remain
32 valid.

33 (H) *Advise the person signing the authorization of his or her*
34 *right to control the use of his or her genetic information.*

35 (I) *Advise the person signing the authorization of his or her*
36 *right to revoke authorization at any time.*

37 (J) *Advise the person signing the authorization as to whether*
38 *his or her information will remain identifiable or whether measures*
39 *will be taken to make the information nonidentifiable.*

1 (K) Advise the person signing the authorization that the genetic
2 information and sample provided must be destroyed upon achieving
3 that purpose.

4 ~~(8)~~

5 (L) Advise the person signing the authorization of the right to
6 receive a copy of the authorization.

7 (2) Any person who collects, stores, analyzes, or discloses the
8 genetic information of an individual shall comply with all of the
9 following:

10 (A) The person may not collect, store, analyze, or disclose the
11 genetic information for any purpose other than the purpose
12 authorized by the individual to whom the information pertains.

13 (B) Once the specific purpose authorized by the individual to
14 whom the genetic information pertains has been fulfilled, the
15 individual's genetic information and DNA sample shall be
16 destroyed.

17 (C) The person shall permit an individual to revoke an
18 authorization signed pursuant to paragraph (1) at any time.

19 (D) The person shall provide an individual who has signed an
20 authorization pursuant to paragraph (1) with a copy of that
21 authorization upon request.

22 (h) (1) Genetic information may be collected, stored, analyzed,
23 or disclosed without the authorization required by subdivision (g),
24 in accordance with paragraph (2), provided that the entity may
25 collect, store, analyze, or disclose the information only for the
26 purposes specified. Use for any other purpose is subject to the
27 authorization required by subdivision (a).

28 (2) Genetic information may be collected, stored, analyzed, or
29 disclosed under this subdivision, as follows:

30 (A) By a law enforcement official or correctional officer in the
31 execution of his or her official duties consistent with existing law.

32 (B) By a hospital, laboratory, or physician carrying out
33 court-ordered tests for genetic information.

34 (C) By a licensed health care professional, as defined in Section
35 56.05, in a medical emergency.

36 (D) By a coroner or medical examiner, in the execution of his
37 or her official duties consistent with existing law.

38 (E) For purposes of any screening of a newborn infant required
39 by state or federal law.

40 (F) If the information is in the form of deidentified data.

1 (G) By any person or entity covered by and required to comply
2 with any of the following:

3 (i) The Health Insurance Portability and Accountability Act of
4 1996 (Public Law 104-191).

5 (ii) Section 56.11 of the Confidentiality of Medical Information
6 Act (Part 2.6 (commencing with Section 56)).

7 (iii) Section 791.13, 10123.35 or Article 2.6 (commencing with
8 Section 10146) of Chapter 1 or Part 2 of Division 2 of the Insurance
9 Code.

10 (iv) Section 50.25 of Title 21 of the Code of Federal
11 Regulations.

12 (v) Section 46.116 of Title 28 of the Code of Federal
13 Regulations.

14 SEC. 3. No reimbursement is required by this act pursuant to
15 Section 6 of Article XIII B of the California Constitution because
16 the only costs that may be incurred by a local agency or school
17 district will be incurred because this act creates a new crime or
18 infraction, eliminates a crime or infraction, or changes the penalty
19 for a crime or infraction, within the meaning of Section 17556 of
20 the Government Code, or changes the definition of a crime within
21 the meaning of Section 6 of Article XIII B of the California
22 Constitution.